

Our Voice

The Newsletter of Autism Network International

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Here it is: the first issue of our very own newsletter. This is only the beginning. The formation of Autism Network International represents an unprecedented step in autistic self-empowerment. This is an entirely autistic-run organization. It isn't being provided for us by non-autistic people. We're not being sponsored by any other organization. This is an *independent, self-help* network. It's up to us to make it fly.

We do have subscribers who are not autistic. We welcome them, in the spirit of increasing understanding and communication between autistic and non-autistic people. This premier issue contains a letter from parents seeking to better understand their autistic child. My personal thoughts about the issues they raise form the basis for this issue's editorial. I encourage readers to respond with their own thoughts.

Along with the exciting possibilities for peer support and adult autistic role models for autistic children, this issue raises the serious concern of exploitation and abuse of autistic people. This is unfortunately a very real and widespread phenomenon, and we need to learn to protect ourselves. I have asked an advocate at a domestic violence organization to send some information about recognizing and dealing with abuse. This material will be included in future issues. Again, I encourage readers with relevant experience to contribute their ideas.

As a self-help/peer support network, it is of utmost importance that ANI remain a safe forum for our members. There have been several instances that I know of in which people representing themselves as advocates, mentors, or supporters of autistic people have infiltrated support groups and computer networks and have victimized autistic people and their families. Members are urged to *be cautious* about people you meet through ANI, just as you would be cautious when meeting strangers

anywhere else. In particular, if there are any incidents of misuse of the directory (available only to autistic people) or of people engaging in inappropriate behavior while acting as speakers or consultants, please notify me immediately.

While there is no way to guarantee against these things happening within ANI, I am setting up some procedures to make them less likely:

1) Anyone wishing to be included on our referral list as a speaker or consultant will be required to provide proof that he or she has a valid diagnosis of autism, PDD, or Asperger syndrome. This is as much for our own protection as for the benefit of people who wish to engage an autistic speaker. Certain people who don't want to hear what autistic individuals are saying have established a pattern of trying to discredit those individuals by claiming that they're "not really autistic." I feel that our members shouldn't have to find themselves in a position of having their validity publicly challenged while they're sharing of themselves and trying to help others by speaking out about their experiences. When our referral system is in place, we will be able to document that anyone we refer as a speaker does indeed have the diagnosis.

2) Anyone wishing to be included on our referral list will be required to provide personal references, just as you would for a job or any other volunteer position where trust is an issue. These references will be checked before the person is accepted as a consultant.

Autistic members who have expressed interest in being speakers or consultants will be contacted within the next few weeks about these guidelines.

Well, here's the beginning. Let's keep it up!

Jim Sinclair, ANI Coordinator

COLLEGE LIFE FROM AN AUTISTIC PERSPECTIVE

by Becky L. Brock

There are many problems facing high-functioning autistic people, and there is no one solution to these problems, as there is not a single possible solution to most problems facing "normal" individuals. The suggestions which follow have been helpful in my experience in college, but many can be applied to high school and other situations as well.

In the past few years more and more autistic people are attending college. As a result the question often arises as to what type of school is best. I have attended a small private college as well as large universities. I began my college career at Austin College, a church-affiliated college in Sherman, Texas with an enrollment of 1200, and received my B.A. in history after three years. Then I went out of state to attend Indiana University, which has an enrollment of over 30,000, to pursue my master's degree in history. I also spent a year at Arizona State University, which has a student population of approximately 45,000.

Should an autistic person attend a small or large school, a school close or far away from home, a private or public school, etc.? What special programs should the college offer, such as disabled student services?

Personally I feel that an autistic person should begin his or her college career at a smaller school. A smaller school generally offers smaller classes and more interactions with professors. The bureaucracy at smaller schools is much easier to deal with. An autistic student can later transfer to a larger school once he or she becomes adjusted to the college system. I completed my degree at the smaller school and then went to a larger school for graduate work. At the graduate level a larger school is often necessary, but it is easier to deal with if the initial adjustment to college life has already occurred.

The feature I found most helpful at my undergraduate school was a college orientation course that was mandatory for all entering freshmen.

Each class was taught by a faculty member and had about 20 students. This course covered topics such as using the library, study skills, registration, and using school facilities and services. At Austin College these professors strived to have a good relationship with their advisees, and often sponsored social activities such as parties. A student's faculty instructor in this course also served as the academic advisor, although students were permitted to change advisors in subsequent semesters. A student could then select any faculty member as advisor (with that person's approval), regardless of major, and therefore students could have an advisor with whom they felt most comfortable. It is important for a student to have an advisor he or she can trust, since the advisor can help solve minor academic problems before they become major problems and frustrations.

In addition to an academic advisor, I recommend that autistic students see a personal counselor on a regular basis. The level and type of degree the counselor has is not important, but the autistic person must feel comfortable with him or her. However, the university counseling center should be avoided, particularly at larger schools, since they are incapable of meeting an autistic person's needs. Finding a counselor has been one of my major problems, since I don't know many people in the general community and the disabled students office refers students to the university counseling services.

Another question is what kind of student services should a college/university provide. Since autism is a disability, the disabled student services office at a school can provide help in some situations. However, I question how much assistance they can provide for an autistic student. If the autistic person has other disabilities as well they can be of great help. Since they handle very few autistic students they are not really prepared to deal

with the special needs caused by autism. In fact, I feel that a disabled students office isn't necessary for an autistic student, particularly at a smaller school. My undergraduate school lacked a disabled services office, yet I feel that my needs were better served there than at the schools with disabled services because personalized services were available to all students. In addition, autistic people should learn to work with "regular" services whenever possible rather than relying on special help.

Academically many autistics can do well, although they have their strengths and weaknesses like everybody else. They should be encouraged to pursue the subjects in which they excel. I participated in the Advanced Placement program, which allowed me to earn college credit by examinations, and as a result I earned my undergraduate degree in three years. Nevertheless, an autistic student should consider career possibilities when selecting a major; otherwise there will likely be problems in finding a job. I fell into this trap with my history degrees, and despite my education I am still undecided about my career. Autistic students should avoid courses in areas that are particularly difficult if possible, and if that is not possible there are creative ways to make the required courses easier. For example, one of my limitations is in foreign languages, but reading knowledge of at least one was required for my master's degree. I failed in a standard German class. Therefore I fulfilled my requirement in a less popular language (Polish in my case), where the number of students was so few that the instructors often go out of their way to retain students by tailoring the class to each student's needs.

Do autistic students need special accommodations? The disabled students' offices generally recommend tutoring; however I find that reviewing material by myself is more effective than tutoring in most situations. Other autistic students do find tutoring helpful, so it probably should be tried in classes where the student has

problems. It is very important that the autistic student be provided a nondistracting environment in which to study. At Indiana University there were soundproof booths available in the library for disabled students, and I found them very helpful. Autistic students should also have liberal access to a computer, and preferably should have their own to use at their convenience. I use my computer not only for writing papers but also as an aid in studying. I will often type my class notes into the computer as an active method of review. Most schools have computers available for student use, although I found these computer labs to be too distracting for studying or completing assignments.

The question also arises as to where an autistic college student should live. There are several options, including residence halls, apartments, and living with parents. I lived in college residence halls for seven years, and found that it provided the atmosphere for me to make great advances in my social skills. I had roommates for the first two years, but my school used personality inventories to match roommates so that fewer incompatible matchings would occur. Both of my roommates were reasonably compatible and lasted for their respective school years. Unfortunately most schools just match roommates randomly, and it is very likely that an autistic person will not click with his or her roommate. I spent the last five years in single dorm rooms, which gave me more privacy and independence. It is also important to check the reputation of each dorm at a particular school, since some dorms are very noisy and should be avoided by autistic students. The disabled students' office may be able to help in this regard. Upperclassmen and graduate dorms should be strongly considered if the student is eligible. I lived in a graduate dorm while I attended Indiana University, and found the atmosphere very conducive to making lasting friendships. This year I am living in my own apartment, but I find that my social life has been seriously curtailed. Other autistic

people prefer apartments to dorms, but they are likely to miss out on "social education." Apartments do offer an opportunity to develop independent living skills. The transition from living at home to living alone may be too sharp, and living in a dorm also provides a buffer period of partial independent living. Some autistics prefer to live at home, but the sheltered environment hinders the development of social and independent living skills. I would not recommend it unless financial or other circumstances make it necessary.

I have found that my greatest challenge has not been from academia but from other medical problems. Many autistics are bothered by health problems, and because of an autistic person's easy distractibility the symptoms are more bothersome and disabling than in an average person. When I am physically ill my ability to concentrate on my studies is seriously impaired, and since I have chronic allergies (as many autistics do) my performance and grades have been

adversely affected. Nevertheless, many doctors and other professionals were eager to take the easy answer and blame my problems on autism or "psychological problems," and thus ignored or misdiagnosed my real underlying problems. I would then become frustrated over the state of my health, and thus my problems would become even worse and led to a vicious cycle. Therefore maintaining optimal health is very important for an autistic person.

I have provided an outline of major problems and possible solutions facing autistic college students. Nevertheless, other problems will surface during any student's college career, and should be tackled with creativity and an understanding of the person's individual abilities and needs. An autistic student should not be underestimated, and should be encouraged to pursue his or her goals.

PROCLAMATION OF ACT OUT
by Laurie Lacey

Until there is DIGNITY and RESPECT there will be ACT OUT.
ACT OUT stands for Autism Coalition To Overthrow and Undo Tyranny.
We're tired of being scapegoated, institutionalized, segregated from our nonhandicapped peers, forced into sheltered workshops for the retarded—which are nothing but sweatshops by government agencies—being denied government benefits that are rightfully ours such as SSI, Social Security Disability, Vocational Rehabilitation (job training) which is OUR TAX money at work, and last of all being TORTURED! I've experienced some torture by my peers as a child but that is nothing like our institutionalized brothers and sisters experience. It is HIGH TIME we resist for our sake and Earth's sake.

AUTISM AND SEXUAL ABUSE
by Kathy Lissner

(This article originally appeared in the Fall 1991 issue of the newsletter of the Greater Philadelphia Chapter of the Autism Society of America, and is reprinted here by permission of the author.)

There are many movements now that deal with abuse and date rape. Several times the news mentions a William Kennedy Smith or Mike Tyson being on trial or a trial date being set. But, despite the publicity, there is one facet that is absent from this debate and that is the abuse of disabled people, particularly people with communication disabilities. This issue is touchy at best when heard about and even more so when it affects a loved one, especially if that loved one has autism.

I know about this because it happened to me as a child and an adult. As a child I was raped by a neighbor's grandfather who lived two houses down from me. This happened over a period of about three years. At that time, I had no idea that what was happening was wrong. All I knew was that it was awfully damned uncomfortable. As an adult, I've had guys expose themselves to me; I've been attacked; in college I dated a guy once who tried to get me drunk on tequila and we went to my place and he tried to have sex with me. And as recently as last year, the guy who lived next door tried to do it by pulling down his undies, exposing himself in my kitchen. (Thank God he moved to L.A.!) When he did that, it scared the living crap out of me. I pushed him out the door, and said I am not a Kuwait to be invaded. Later that night I called my counselor and told her what went on.

Even though I am high-functioning and verbal, I still have problems deciphering non-verbal behavior. And this makes me a target for sexual abuse. Somehow I'm giving off signals about my vulnerability to those who wish to abuse it. And it makes me think that if this can happen to me, it most likely can happen to a person with autism who isn't as high-functioning or is non-verbal. And usually when sexual abuse happens, it

is done by someone the victim already knows. This makes a person with autism an easy target because of the lack of ability to communicate.

How can a loved one tell if the autistic one has been sexually abused? First, there may be changes in sleeping or eating patterns. Second, if a person with autism is scared of a place, situation, or person he/she previously liked, or suddenly acts differently around any one of these, it may be time for a closer look. Third, if the person is verbal, it could be detected by noticing what he/she is fixating on. Fourth, there may be a major personality change. However, at times there could be no dramatic changes at all. My belief is that it is hard to tell if sexual abuse has happened to a loved one with autism because of the inability to communicate. It took eight years after the childhood stuff happened to me to tell my family about it, and as for the adult incidents I just recently told some of my family members. Luckily, I am in a support group and receive counseling.

There are three reasons why I am bringing this touchy issue up. First, I believe it needs an open forum for discussion and debate because the more it's talked about, the more chance that another person with autism can be helped or protected from abuse happening to him/her. Second, parents, siblings and professionals need a reminder that they should bring up ideas on how to protect the autistic one from being abused, and teach appropriate sexual behavior, even self-protection. And third—for me—what ideas can I gather to protect myself, keep from giving off the wrong signals, and even attempt to read body language? I also think that, in counseling people with autism about signals and vulnerability that might get them in trouble, we have to be clear that it's *never* the fault of the person who is abused.

Had no word for these feelings, looked at the fire and knew,
The word was "consumed". I felt consumed.

I'm on the verge. On the verge of a step.
It's just a step but my mind says "do or die", "do or die",
With the word "DIE" in big letters to scare me off and tell me not to try.

I wish I was in awe of, blinded to stare only at the word "do".
I wish the fire within me was one of motivation and not of self consumption,
Shrinking, shrivelling, tumbling back on myself,
In the face of that big word "DIE".

Come to rescue fear please anger.
We will turn outwards. We will scream, "it's not fair" and break outwards.
We will carry sadness away from the blackness of unsalvageable forever.
We will survive.

And here lies the greatest sadness.
For in the light I came to see, there was no "we".
I was alone.

The only answer, the only safe place left to go,
lay in reaching outward and upward, to the next step.

Donna Williams

SOME QUESTIONS FROM PARENTS: ON BEING DIFFERENT
by Karen and Arnold Resnick

(The following is excerpted from a letter to the editor. Autistic readers are encouraged to send their personal responses for publication in the next issue.)

Your goals sound terrific. We thank you for letting us "listen in" on all the exchanges of views and feelings that will go on on ANI. If we send messages of our own, we will be very careful to respect the main purpose of the network: it is mostly for autistic people themselves.

We are especially excited about the Big Pals network. What a fantastic idea! As soon as our autistic daughter (Abby) learns to read and type, we will purchase a modem so she may participate. We have heard that adolescence can be a particularly stressful time for autistic people—as it is for most children—but having a positive role model to communicate with, one who understands what is going on, should make it easier. This one program could probably do more good than anything that the school system has to offer. In fact, by linking together a mentor and a child, you may be making a big difference in the way people with autism feel about themselves.

As I wrote before, we are interested in how various therapies have worked for people with autism. What therapies do people with autism feel have the greatest benefit? We have read many clinical studies (or summaries of them), and we have seen the effect of DMG on Abby, but we would like to know how it makes her *feel*—and feelings are not something she is able to talk about.

Another thing is very important to us as parents of an autistic child:

We also want to know when people with autism became aware that they were different, and how they felt about it. (Please understand that when we say "different," we don't intend to mean "worse" in any sense.) For example, how and when did it happen to you? Was it traumatic? In what ways did you feel different? (And how does that compare to the way you feel now?) How difficult was it to adjust to the knowledge? What things particularly bothered you? Was there anything that could or should have been done to help you?

We are aware that these questions are personal, and will understand if you decline to answer. But we have good reasons for asking: Abby is 5 1/2, and a very sweet, mostly happy child (especially since she started DMG). We would like that happiness to continue. But we also expect that at some point she will discover that she is different from other kids. The information you gather about these issues will be incredibly valuable to us (and to all parents of autistic children). We would be very grateful to have it.

We love our daughter very much and want to do what will be best for her. In spite of all the research that has been done, there is really very little guidance on how to raise a child with autism, and an adult with autism should know more than anyone else. We want you to know that we are very grateful to you for your efforts in setting up ANI.

SOCIAL USES OF FIXATIONS

by Jim Sinclair

There's a phenomenon I first observed during my first encounter with other high-functioning autistic people, and it really became obvious last February when I spent a weekend with other autistic people: the use of personal fixations to make interpersonal connections.

I first observed this at the 1989 TEACCH conference, when I was introduced to some other autistic people who lived in a TEACCH-managed group home. These people weren't really all that "high-functioning" compared to many of the people I've met since then, at least in terms of their conversational speech. But they talked fluently if not interactively, and it quickly became obvious that they had a geography fixation. They had a *shared* geography fixation: two autistic people living in the same group home had the same fixation. I suspect that was more than just coincidence; it indicated some kind of interaction and sharing of interests.

As soon as they found out I had driven in from Kansas, they wanted to know what highways I had taken. They knew the roads between Kansas and North Carolina better than I did, despite the fact that neither of them could drive. They talked about different possible routes and what cities each route would have taken me through. Of course I couldn't follow the conversation because I'm absolutely terrible with geography and usually don't even know where I am, let alone how I got there—but I could still recognize this as an attempt to relate their interests to my travel experience.

The next day one of them approached me and began talking (rambling would be a better word) about how he had looked up the names of all the counties in Kansas and North Carolina in his almanac. He went on and on, rather disjointedly, telling me the name and publication information of the almanac, so I tried to focus him by asking, "What did you find? Were there any counties with the same names?" Unfortunately, his focusing

problems prevented him from recognizing this as a suggestion that he could make his point without all those background details; he just experienced it as an interruption that made him lose his place so he had to start all over again. This time I waited quietly through the interminable buildup, and he eventually did get to the point and tell me that he had found ten county names that occurred in both North Carolina and Kansas. He recited the list of names. Then he turned to another autistic person he had just met that day. She was from Michigan, and he told her he was going to look up Michigan county names when he got home that evening.

This person had some significant problems with conversation. His speech was generally non-interactive and extremely perseverative. But in spite of being fairly limited to speaking non-interactively and perseveratively, he was using his fixation to try to make a connection between himself and other autistic people he met.

Now I know other autistic people who have considerably better conversational skills than that, and I've observed some fascinating uses of fixations to make connections. For example, Kathy is fascinated by anything having to do with Russia or the Soviet Union. A few months ago I received a letter from another autistic person who had met Kathy and me in Indianapolis last summer. Part of the letter read, "Please give my regards to Kathy. I have thought of her so many times as events occurred in Russia and the Soviet Union." I had also thought of Kathy when I saw news stories about those events (and my own interest in international politics—or any other kind of politics—is practically nonexistent). Both of us had used our awareness of Kathy's fixation to be able to recognize things that would be of interest to her.

Kathy is also aware of the fixations of her other autistic friends. When I visited her apartment, I wasn't

surprised to see the walls covered with maps and flags and clippings from Russian newspapers. I had seen Kathy become completely transfixed by a display of flags at a conference, and I had been nearly deafened by her shrieks over the phone when she called me while watching the Olympics and seeing a parade with the flags of all the countries represented there. But along with all the things relating to her own fixations, I also saw some artwork on her walls which I recognized as being the work of other autistic people. I recognized some of Jessie's paintings of street lamps, and one of Barbara's traffic lights. Kathy says she thinks she can recognize which traffic light it is. I don't know Barb well enough to be able to tell her traffic lights apart or to understand much about what they mean to her, but I did recognize that it was one of her traffic lights. Kathy is friends with Barb, so she has learned more about the traffic lights because they're important to Barb.

Another example: Even before I met Donna in person I had recognized that she must have some visual fixations, because she would always enclose some shiny or brightly-colored object in each of her letters. When I was going to meet her, I thought of bringing something shiny as a gift, but I didn't have enough of a feel for it to know what would be appropriate. Then during the time I spent with her, I watched her go into fits of ecstasy while arranging colorful objects and

looking at them through a kaleidoscope. She later described the feeling as "orgasmic"; the word had also occurred to me while watching her. (Donna is asexual; she was referring to the intensity of the sensation, not to some bizarre erotic fetish.) And while she was engaging in this activity of arranging objects and looking at them through her scope, *she kept insisting that Kathy and I look at them too*. Of course, being autistic I'm not supposed to understand things like this, but to me that looked suspiciously like a person wanting to share a pleasurable activity with her friends.

And for my part, having seen her reach the peak of rapture over an empty Coke can, and having heard her say that metallic red was her favorite visual stimulus, I knew what would be an appropriate gift for her. I got a red sequins-covered belt from K-Mart and sent it to her: pretty tacky from a fashion perspective, but just right for someone with her sensory responses.

The common factor here is that the activities and interests that high-functioning autistic adults use to share their own pleasures and to relate to each other's experiences are often the very activities that people try to eliminate in low-functioning autistic children: "stimming" on sensory fixations and perseverating on subject fixations. These autistic behaviors are generally considered to be isolating and detrimental to social interaction. Yet here we are using them to facilitate getting to know each other.

CAN AUTISTIC PEOPLE HAVE INTIMATE RELATIONSHIPS?
by Kathy Lischer

Too often I hear and read that people with autism don't know how to form close relationships with people or how to be intimate with someone. Whenever I read this, or when I read the MAAAP, and see a person with autism wanting a boy- or girlfriend, I think that person can have a relationship like that if only given a chance and a lot of help. I am lucky in that right now, I have a boyfriend, Ray.

Ray is a 39-year-old guy originally from Detroit, Michigan. I met him two months ago when my friend Donna Sieve introduced me to him. The reason she wanted me to meet him is that we both like Star Trek and science fiction. Also, Donna knew about my background and said that Ray is a gentle guy. From that, we met each other and started to get to know one another, and the more we know each other, the more we want to be with each other. Ray has met all of my family except for my sister in Florida and brother in California, and they are all impressed with him. That means much to me because I know that when I get close to someone, I want that person to be liked by my family.

When I was younger, I took it for granted that when I got older I would have a boyfriend. After all, I saw my brothers and sisters date, fall in love, and get married. And naturally, I thought I'd do the same. And right now, I'm getting to

understand what they went through when they were in this process. I remember when I was 18 I talked to my sister Jenny about what kind of guy I wanted to be with. I knew back then I wanted a patient, non-temperamental, and gentle guy. I didn't want to go out with someone who is impatient or who has a temper. And Ray has the kind of personality I like. The only difference is that as I got older, I thought the guy I would go out with would have blond hair because I got close to two guys (one in college and one in New Jersey) who were gentle guys with blond hair. Ray is an African-American guy, so he has black hair. But his personality is great, and his eyes are very gentle. Too often I look at other guys' faces and see a hard look about them. I like Ray's gentle look. That means a lot to me.

Ray and I talk a lot about very deep issues because he knows I have been abused as a kid and as an adult. We spend much time discussing very intimate and deep stuff to get an understanding of how we feel about each other and why. We are very open in our communication and explain to each other many different things. Ray also knows about my autism and wants to learn more and more as time goes by. I also want to know more about Ray and his background, because the more we get to know each other, the more we each appreciate the kind of person the other has become.

Autispeak

This is the language we speak,
we who can talk without sound.
This is our voice in the silence
Where every word has weight, and no thought is ever lost.

This is the language we speak,
we who embrace without touching.
This is our dance without bodies
Where every touch has meaning, and no glance is ever wasted.

This is the language we speak,
we who can see without looking.
This is our star behind darkness
where velvet rainbows sing, and no tear falls unseen.

This is the language we speak,
we who can float outside time.
This is our home beyond nowhere
where shadows' footsteps fall,
where memory echoes from the future,
and comfort flows back from the past,
where smiles have no need for faces
and warmth breathes from the frozen places.
This is our source, our destination
where every song is heard, and no soul shines unknown.

Jim Sinclair

HELPFUL HINTS

This is a column where members share practical coping tips. If you've found some way to deal with an autism-related problem of everyday life, please write a brief description of the problem and your solution and send it to be printed here. Your solution might be able to help someone else who has the same problem! If you have some difficulty in everyday life and you'd like to know how other autistic people cope with it, send a brief note to this column. Someone else who reads it might have an idea for you!

This tip comes from Donna Williams. It's the wording for a card an autistic person can carry in case of emergency, or in case he or she becomes unable to communicate for any reason. Donna's card contains information that is relevant to her. You can modify the wording to fit your individual circumstances and needs.

My name is _____. I am autistic.

I may get into panic states, overload or shutdown. In these states I may lose sense of direction and familiarity with my surroundings and my purpose for being there. I may also lose speech including comprehension. At such times my senses are painfully sharp so:

DO NOT TOUCH ME OR TRY TO CONTROL ME
LEAVE ME ALONE OR STAND AT A DISTANCE
SPEAK QUIETLY AND SLOWLY *ONLY* IF NECESSARY.

- * It may be useful to encourage me to breathe deeply and slowly.
- * It may also be useful to non-verbally draw my attention to that which I will find familiar: grass, leaves, sticks, the surfaces of things. This may help me get a grip on my surroundings again.
- * There is no need to call for help. This will only make me worse.
- * This is not a psychiatric condition so I do not need a psychiatrist.
- * These states can last between 15 minutes to an hour and may be made up of short bursts which will peter out.
- * IF I RUN, *DO NOT* CHASE ME.
- * If I am calm and secure where I am, leave me there.
- * If my surroundings are making me anxious, suggest a walk with you (in an open area) as I may otherwise lose direction and familiarity with where I am.

EDITORIAL: What Does Being Different Mean?
by Jim Sinclair

Autistic people are different from other people. We hear that all the time, but what does it really *mean*? To non-autistic people, including most of our parents and teachers, being different is one of the most disturbing things about autism. A treatment program is considered successful to the extent that it causes the autistic person to act more like a non-autistic person. An autistic person is considered successful to the extent that he or she has learned to "act normal." But what do being different and being normal mean to us?

Karen and Arnold Reznick ask when I developed an awareness of being different. My answer is that I still haven't, at least not in the sense they're talking about. I just didn't start out with an expectation that I *should* be the same as other people. I grew up surrounded by a lot of things that weren't like me—parents and other adults, dogs, hamsters, trees, flowers, furniture—and it never occurred to me to be surprised that they weren't like me. Other children were just one more category of things in the world. It didn't occur to me that I was supposed to be one of them.

What *has* come as something of a revelation to me (and it didn't happen until after I had graduated from college) is that *other people DO expect me to be one of them*. This was quite surprising to me, and it seemed more than a little bit ridiculous when I realized it, and I still don't really understand it.

There were some things I was aware of from a much earlier age. I noticed that other kids picked on me. That was just part of life: I didn't like it, and at times I wondered what there was about *them* that made them so nasty, but I certainly didn't think that I should be like those nasty people.

I remember my mother urging me to "be nice to them and then they'll be friends with you." I didn't know what

she was talking about. Be nice? I wasn't doing anything to hurt them. I wasn't interfering with them in any way. I was just minding my own business. What more did she want from me? And I certainly didn't want them to be friends with me. I didn't like people who treated me that way; why on earth would I want them as friends? (I should add that there were a few kids who were nice to me, and I did value their friendship. It didn't occur to me to group them together with the kids who picked on me either.)

I've heard other autistic people say that they wish they weren't so different from other people for this reason: that they don't like being mistreated, and they know the reason for the mistreatment is that they're different and don't fit in. I never reached that conclusion myself (why should I be unhappy with the way I am just because the way some *other* people are is obnoxious?), but I can understand the reasoning. They want to be more like other people because of some perceived benefits that go with the status of fitting in, not because fitting in is especially desirable in itself.

The idea of wanting to fit in for its own sake, of being different as a misfortune in and of itself, is not an idea I've heard expressed by autistic people. If an autistic person is unhappy about being different, it's because non-autistic people have taught the autistic person that bad things will happen to you if you're different.

I've talked about peer mistreatment, but from what I've observed, some of the most devastating consequences of being different are inflicted by parents and others who believe they're acting out of love. What message is conveyed by parents who constantly express sadness over their child's differentness from other

children? What is communicated by parents who constantly exhort their child to "act normal," and whose greatest praise and approval are gained by "not acting autistic"? The unmistakable message is, "My parents don't want me the way I am. They're sad that they have me instead of a normal child. The only way they'll like me is if I act like somebody else."

Some autistic children internalize this message and accept "being normal" as their major goal in life. And it's been my observation that the more deeply invested an autistic person is in being normal, the more likely it is that he or she suffers from anxiety, depression, and low self-esteem. It's a natural consequence of making one's top priority to become something other than oneself.

So what do I suggest? First of all, I think everyone needs to realize that being autistic is nothing to be sad or ashamed or embarrassed about. Stop grieving about it! Secondly, I think non-autistic people need to stop agonizing over issues of normalcy and differentness, and autistic people need to stop getting caught up in non-autistic people's hangups over these issues. Stop trying to deny or minimize the differences, and stop pretending the autism can be separated from the person. Autistic people are very different from non-autistic people, and those differences run all the way down to the core of personality and awareness.

And there's nothing wrong with that! It's our nature as autistic people to be different in those ways—it's the way we're *supposed* to be. Feeling sad about the mere fact of being different is a handicap that non-autistic people have. It's not our problem, and we need to stop allowing it to damage our self-concepts. Besides, even though non-autistic people may hate or fear or pity us for being different, I think they really need us to be just the way we are. We're the ones who notice that the emperor isn't wearing any clothes.

Does this mean I think autistic people shouldn't have any treatment or education? Not at all. *Every* child needs to be taught to function in the world. Every adult encounters problems and challenges from time to time, and needs to learn new skills or seek help from others. My point is that autistic people should be helped to function in the world *as autistic people*, not to spend their lives trying to become non-autistic.

If an autistic person is engaging in behavior that is dangerous or destructive, or that interferes with the rights of others, then certainly this is a problem that needs to be resolved. If an autistic person lacks a skill that would enhance that person's ability to pursue his or her goals, then every effort should be made to teach the skill. The problem I see is when autistic people are subjected to intensive, stressful, and often very expensive treatments simply for the purpose of making them appear more normal: eliminating harmless behaviors just because non-autistic people think they're weird, or teaching skills and activities that are of no interest to the autistic person just because non-autistic people enjoy those activities.

Another important issue in helping autistic people to function as autistic people is that even if an autistic person has the same goal as a non-autistic person, he or she might need to follow a different procedure for getting there. This is what I call working *with* autism, instead of *against* it. Autistic people have ways of learning, ways of remembering, ways of orienting, and ways of working that are different from those of non-autistic people. We should be looking for ways to use our natural processes productively, not trying to do everything the same way non-autistic people do it.

Of course this brings us back to the matter of being different, and not being ashamed of it. Going back to my own personal experience, of course it creates complications when I make use

of my own autistic processes to pursue interests and goals that are meaningful to me, and make no effort to do things the way other people do them. It violates people's expectations. But a lifetime's experience has demonstrated that I have no choice in that matter—I'm going to violate people's expectations no matter what I do, because I don't know how to act normal even if I wanted to.

The choice I have is in *how* I violate those expectations. If I accept other people's norms as my own goals even though I don't understand them, then I assure that when I can't conform to other people's expectations, I fall short of my own standards as well. But if I define myself only in terms that are meaningful to me, and I refuse to accept standards and roles that aren't part of my reality, then I can maintain a strong sense of identity and self-assurance. When I don't meet prevailing expectations of normal behavior, I know and can explain *why* I'm not meeting them: Those norms apply to non-autistic people. Since I'm not a non-autistic person, there's no reason why I should try to act like one, and there's no sense of failure attached to not acting like one.

That might appear to be a separatist posture. Whether it is or not depends on whether the non-

autistic people I encounter are prepared to allow me to live and function among them as an autistic person. It comes down to this:

There are many ways in which it is difficult or impossible for me to meet standard definitions of normalcy. Some of these relate to impairments or deficits in functions that come easily to most people. Some relate to skills or strengths in functions that are difficult for most people. Some relate to ways of perceiving and responding that are neither better nor worse, but are qualitatively different from those of most people. Among my greatest strengths are my inner stability and my strong sense of who I am and what is important to me. Some of my greatest deficits involve my inability to learn and internalize social norms that appear meaningless to me. There has been ample demonstration that I can function more effectively by starting from a position of strength rather than one of weakness: that is, by presenting myself as myself rather than trying to become something else. Given this foundation, is it possible for me to find—or create—a place in society that allows me to make maximum use of my strengths and to minimize the limitations of the things I can't do?

And the answer to *that* will be a lifelong adventure, for all of us.

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Autism Network International
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